

MCS Selective

Dementia: The Great Moral Challenge

Catalog Description: “Dementia” is technically a syndrome (a cluster of symptoms), involving a decline from a former mental state that is considered irreversible. It is secondary to many disease causes. A century ago the major cause of dementia was syphilis, and specifically neurosyphilis. Today, because people live longer on average, diseases of old age such as Alzheimer’s, Parkinson’s, Pick’s, Creutzfeldt-Jakob, and others are the causes of dementia. There can be genetic factors both causal and risk related, vascular factors, and even protracted stress can contribute to hippocampal atrophy.

Instructor



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Syllabus

Part One: Ethical Issues Along the Progression of Illness

There are countless ethical issues that come into play along the progression of dementia. We will discuss many of them, all of which also involve caregivers, society, and larger questions around human dignity. Some sample questions are these, but student can also come up with their own and should:

- Q1. Should we break the news to Grandma? Should we use the “A” word and when?
- Q2. How quickly will I decline?
- Q3. Are there really any effective drugs to stop this disease?
- Q4. Can our tender loving care make a difference and even slow down progression, or is it all just genetically pre-determined?
- Q5. Should we tell other people about my diagnosis?
- Q6. Will “I” still be there, more or less, despite the silence or confusion?
- Q7. Will I “suffer”? Will I be overtreated against my will?
- Q8. Do I really want to continue to treat my heart failure or diabetes or dialysis or cancer as this disease unfolds?
- Q9. Will I be a burden to those who take care of me?
- Q10. Is genetic susceptibility testing a good idea?
- Q11. Should I file a living will or a durable power of attorney for health care?
- Q12. Will my remaining ability to make choices be respected?
- Q13. Can I avoid being physically or chemically restrained?
- Q14. Can I drive and for how long?
- Q15. Should I participate in research?

- Q16. What happened in the T-4 hypothermia experiments in Nazi Germany when an estimated 40,000 people with dementia were eliminated by being taken out of asylums and left to freeze to death? The description of them as “life unworthy of life” and as “useless eaters” might be expected as an expression of hypercognitive values.
- Q17. Can I avoid technology and tubes so I can just die naturally?
- Q18. What is the secret to avoiding the intensive care unit and hospitalization in favor of hospice?
- Q19. What about the option of pre-emptive assisted suicide in Europe and Canada? Can this be done in places as close as Maine and New Jersey for those who cannot afford to fly to Switzerland’s facility called *Dignitas*?
- Q20. What if the nature of “hope” in the context of progressive dementia?
- Q21. Where do music, art, and poetry fit into successful caregiving?
- Q22. Why is symbolic rationality more important than linear? What is the difference?
- Q23. What about the use of feeding PEGS? Is this a good idea? Is it ethical? Why do so many people frown on such use of technologies in this population?
- Q24. What is the moral significance of consciousness, and why might it be more important than “mind” or rationality?

Part Two: A GREAT CHANCE FOR STUDENTS TO PUBLISH BASED ON NEW DATA.

In the summer of 2023 Post (PI) and a team from Harvard Chan, the Gallup Organization, as well as Baylor Med completed the first national survey of caregivers for deeply forgetful people, primarily diagnosed with Alzheimer’s Disease. This was the first national survey in the history of research on the experience of dementia, on caregivers, and on the important episodes of “unexpected lucidity.” We will examine this survey instrument, and several of the papers that are arising from it. The data will be made available and students are free to form teams to develop publishable papers with Post’s mentorship.

Readings:

We will have one easily readable and enjoyably brief book that brings together 30 years of work and study with deeply forgetful people and their caregivers. This will be given out free of charge.

Dignity for Deeply Forgetful People: How Caregivers Can Meet the Challenges of Alzheimer’s Disease (John Hopkins University Press; May 31, 2022). Post, recipient of the Alzheimer’s Association Distinguished Service Award, shifts the focus from finding a cure for Alzheimer’s to seeing and connecting with the whole person—their core personality, preferences, emotions, creativity, and capacity for joy—despite the limitations of dementia. An advocate for “deeply forgetful people” since the early 1990s, Post teaches caregivers and professionals how to notice the self-identity that always remains, and how to communicate effectively. “We are not in any essential way very different from *them*,” Post drives home, “unless we choose to overvalue linear rationality and independence, to overlook their many other human qualities, and to pretend that we are not all ultimately vulnerable and interdependent.” With a powerful endorsement from His Holiness the Dalai Lama, the book title says it all: *Dignity for Deeply Forgetful People*. Post avoids the word “dementia” because it is a negative term, much like the word “retard,” one exclusively about decline from a former mental state that invites oft-heard negative metaphors such as “gone, husk, shell, absent.” Post prefers the term “deeply forgetful people” as a language of inclusion, placing us all on a continuum a community of human dignity.

How can we approach a "deeply forgetful" person so as to notice and affirm their worth and dignity? How can we all become open to their surprising expressions of self-identity? As a culture how can we overcome the adverse influence of "hypercognitive" values, with their hurtful emphasis on human worth as a matter of cognitive strength and memory? This bias, Post suggests, is responsible for the mistreatment of this population, including the injustice of providing them and their devoted caregivers with mere social-economic "scraps" or "leftovers."

Drawing on evocative caregiver vignettes, Post affirms a new appreciation for the emotional, creative, musical, artistic, and underlying selfhood of these "differently abled" full human beings. Such a shift allows forgetful people to teach us compassionate care. Post urges family members and professionals to find hope in noticing continuing self-identity regardless of race, culture, or socioeconomic factors. He shares impressive strategies for better communication with loved ones, and advocates for a nationally supported caregiver respite program.

His phrase "unexpected lucidity" stresses the awesome moments of remarkable insight that are stimulated by music, art, nature, smell, and even a dementia dog – Post has been a leader in the dementia support dog movement on three continents. He rejects any philosophy that derives moral worth from possessing the rationality of *what we do* rather than from the symbolic rationality of *who we are*. Deeply forgetful people will identify with a meaningful symbolic object all the way to the very end stage, knowing that their identity is connected with a doll they clutch or a cowboy hat they wear or rosary beads they pray.

Grounded in his own caregiving experience, ***Dignity for Deeply Forgetful People*** is also immediately actionable. Post is widely recognized as a clinical and family consultant providing practical moral wisdom for caregivers. For three decades, he has conducted several hundred community dialogues arranged by Alzheimer's programs across the US and around the world, including Japan and India. In everyday language, Post responds to caregivers and affected loved ones on questions they raise:



STEPHEN G. POST, PhD, is Director of the Center for Medical Humanities, Compassionate Care, and Bioethics at Stony Brook University Renaissance School of Medicine, where he also serves as Professor of Family, Population, and Preventative Medicine and Head of the Division of Medicine in Society. He is an elected Member of the Medical and Scientific Advisory Board of Alzheimer's Disease International and one of only three recipients of the Alzheimer's Association Distinguished Service Award. His first book, *The Moral Challenge of Alzheimer's Disease* (Johns Hopkins University Press, 2000) was hailed as a "medical classic of the century" by the *British Medical Journal*. He has been featured internationally in the media, including *The Daily Show*. Post received the United States Congress Certificate of Special Recognition "In Recognition of

Outstanding Achievement" (28 November 2012). He shared the Pioneer Medal for Outstanding Leadership in HealthCare with Dr. Edmund D. Pellegrino, MD (2012). www.StephenGPost.com

Educational Objectives

At the conclusion of this course, you will have the ability to:

1. Be cognizant of and be able to converse about the impact of dementia on the self and its identity.
2. Understand the origins of negative and hostile social attitudes.

3. Understand why and how deeply forgetful people too often are captures by unwanted medical technologies.
4. Discuss many of the ethical issues that arise along the chronological progression of dementia, esp. or the Alzheimer's type.
5. Honestly and openly discuss pre-emptive assisted suicide for individuals with dementia, a growing phenomenon in at least ten countries, including Canada.
6. Learn about how to design a national survey and apply it.

Topics and Dates

Time and Location: 1:00-3:00pm, Room TBD

PART ONE

Week 1 (4/23/24) Questions 1-15 from the above list (Reading Post, chapters 1-3)

Week 2 (4/30/24) Questions 16-24 from the above list (Reading Post, chapters 4-6)

Week 3 (5/14/24) Discussion of Pre-emptive Assisted Suicide in Philosophy and Current Practice (Chapter 7)

Week 4 (5/28/24) Discussion of Students Potential Research Projects Drawing from the National Gallup Survey

Evaluation

Participation and attendance at all sessions is required. Grading is Pass/Fail.

Class size

Minimum 3

Maximum unlimited